

Path to Transformation Concept Paper Comments and Recommendations

Palliative Care Community Partners (PCCP)

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As part of the Patient-Centered Health Homes integrated delivery system (IDS) goals and strategies to "provide the right care at the right time in the most appropriate setting," we recommend inclusion of a community-based palliative care program to address the complex needs of seriously ill Medicaid clients, as follows:

1. Improving overall wellness of the individual patients and panel of patients served
 - a. Providing palliation of advanced symptoms
 - i. recommendations to primary care physicians related to cost-effective, therapeutic, symptom-relieving treatments
 - ii. education with patients and families related to medications and treatment regimens, monitoring for compliance
 - iii. monitoring outcomes and follow up with primary care physicians
 - b. Providing medications reconciliation between various medical providers
 - i. decrease medication errors and polypharmacy
 - ii. decrease costs
 - c. Providing in-home visits by an interdisciplinary palliative care team to meet physical and psychosocial needs, according to preferences of patient and family
 - i. physician
 - ii. nurse
 - iii. social worker/counselor

- iv. CNA/community health worker
- 2. Improving patients' perception of quality of healthcare services
 - a. Identifying patient's goals and focusing on quality of life
 - i. monitoring quality of life, using standardized assessment tool indicators
 - ii. measuring patient's perception of health outcomes, specifically as relates to their individualized goals
 - b. Facilitating shared-decision-making (SDM) between patient, family, and medical team--based on quality of life goals--through new innovative transitions-of-care readiness tool
 - i. initiates earlier transitions of care from invasive treatments to palliative focus
 - ii. decreases futile treatments and emergency/inpatient services
 - iii. improves patient's sense of control and satisfaction with health care
 - iv. reduces costs
- 3. Managing transitions from inpatient to home/community-based care
 - a. removing any barriers to successful symptom management from home
 - i. in-person and phone nursing visits
 - ii. home medical equipment
 - iii. adequate caregiving
 - b. home-based monitoring of symptoms to prevent health crises that would precipitate emergency or inpatient treatment
 - i. tele-health monitoring with nursing follow-up
 - ii. 24-hour on-call, with in-home nursing visits and phone interventions

4. Tracking healthcare savings of individuals served
 - a. monitoring decrease of emergency, inpatient, and aggressive/invasive treatments
5. Tracking patient satisfaction with their health care, and their quality of life

Program Overview:

Palliative Care Community Partners (PCCP) program provides individuals with serious illnesses compassionate, at-home health care, including: advanced symptom management to relieve physical suffering; care coordination to meet comfort, safety and care-giving needs; and an inter-disciplinary approach to improving the overall quality of life for these individuals on physical, intellectual, emotional, social and spiritual levels.

PCCP takes this philosophy of care, that has heretofore been reserved for patients with a prognosis of six months or less through a traditional hospice program, and moves it upstream--where it is often needed most--to all patients who have been newly diagnosed with advanced disease or have reached a time in their course of health care where invasive technology and aggressive treatments are no longer having the desired therapeutic effect and *the burden of care is greater than the benefit*. Palliative care can be introduced concurrent with traditional models of health care, offering alternative advanced symptom management treatments, with immediate and positive outcomes, that promote optimal quality of life. This approach improves the patient's overall wellness throughout their course of health care. And when patients and families are part of the decision-making process--facilitated with their physicians by PCCP--they have improved perception of their overall healthcare experience.

Through partnerships with other community health care and caregiver support services, barriers to having health care needs met at home are overcome, such as poor pain and non-pain symptom management; need for home medical equipment; lack of understanding related to medications and treatment regimens; and inadequate caregiving. Thereby, individuals are able to spend the rest of their lives in the safety, comfort and dignity of home, with improved quality of life, and better satisfaction with their health care.

As an adjuvant or alternative to traditional hospice services, palliative care provides a continuum of physical, emotional and spiritual care for the patient and their family throughout the course of serious illness; during the dying process; and after death, through bereavement support to the families.

Case Study

Having been diagnosed with metastatic cancer, Susan had just completed her third round of chemotherapy. She was constantly in moderate to severe pain, in spite of large doses of opioids; she had been treated at the hospital twice (and the oncologist's office once) in the past two weeks with bowel impactions; and suffered severe breathlessness. The day before choosing palliative care, Susan wanted to take a walk to the mailbox at the end of her short driveway. But she was so weak and short of breath, her husband had to carry her back to the house. But within 48 hours from the initial home visit by a palliative care nurse and social worker, Susan was nearly pain free and able to perform simple activities of daily living again, like loading the dishwasher. A few days later, she and her husband walked to the Post Office 1/8 mile away and back without respiratory distress. And the next incident of constipation was successfully treated at home, without further recurrence, due to good bowel management. Several weeks after palliative care was initiated, Susan was riding a horse again.

As a result of palliative care interventions, Susan's quality of life, overall wellness and perception of healthcare improved immensely. Susan stated that, previously, she felt like "a small fish all alone in a giant ocean. Now, I don't feel alone anymore." Through multiple options-of-care and quality-of-life discussions with the inter-disciplinary palliative care team, followed by shared-decision-making with her oncologist, Susan decided she wanted to stop chemotherapy and continue her life with this improved focus on comfort and quality of life.

As Susan neared the end of her life, she received more intensive palliative care, including care coordination with a home medical equipment provider and extended family members, to keep her safe and comfortable at home. A palliative care Certified Nursing Assistant helped Susan with her personal cares. Her husband received anticipatory grief counseling from a palliative care Licensed Clinical Social Worker and elected to use his Family and Medical Leave Act benefits so he could spend precious time with his wife, as her journey with cancer was reaching the end.

After being admitted to the palliative care program, Susan required no further emergency/inpatient health care services. Since Susan's death, her husband and other family members will continue to receive bereavement care for 13 months.